

A Researcher's Guide to Patient and Public Involvement

A guide based on the experiences of health and medical
researchers, patients and members of the public

Authors

Amadea Turk MSc, research assistant and the Ann McPherson Fellow, Health Experiences Research Group, Nuffield Department of Primary Health Care Sciences, University of Oxford.

Dr Anne-Marie Boylan, Senior Research Fellow, NIHR Oxford CLAHRC, Health Experiences Research Group, Nuffield Department of Primary Health Care Sciences, University of Oxford

Prof Louise Locock, Director of Applied Research, Health Experiences Research Group, Nuffield Department of Primary Health Care Sciences, University of Oxford

Contents

About this guide.....	1
Background to the research.....	2
Definitions, purposes and values of Patient and Public Involvement	3
Purposes and Values of Patient and Public Involvement	3
What can PPI add to different stages of research?	4
Identifying and Prioritising.....	4
Commissioning.....	5
Designing and managing.....	5
Undertaking	6
Disseminating.....	6
Implementing.....	7
Evaluating Impact.....	7
Why members of the public get involved in research	8
Involving People in Research	9
Deciding who to involve.....	9
Finding People to be involved.....	10
Training	11
Training for PPI Contributors	11
Training for Researchers	12
Paying people for involvement.....	13
Practical Advice for Involvement	16
Involvement in practice	16
Clarity	17
Feedback.....	17
Record-keeping.....	17
Training	17
Good Chairing	17
Payment of Expenses.....	17
Catering.....	17
Creating a good atmosphere and long-lasting relationships.....	17
Other Practicalities.....	18
Assessing the Impact of PPI	19
Concerns about Patient and Public Involvement.....	21

Representativeness.....	21
Diversity	21
Long-term involvement and “professionalisation”	22
Feelings about Involvement and Emotional Impact	23
Positive Experiences.....	23
Challenging Experiences	23
Feeling Ambivalent about Involvement.....	24
Colleagues’ attitudes to PPI	24
Involving Senior Colleagues	24
Organisational support and leadership for PPI.....	26

About this guide

This guide is intended for researchers who are interested in involvement, have begun to involve patients or members of the public and want to learn more, have questions about involvement, or are interested in reading a comprehensive overview of the subject based on the experiences of those who are already involved or involving.

The guide was commissioned by the NIHR Oxford Biomedical Research Centre and is based on two research projects about the experiences of patient and public involvement from the perspectives of patients and members of the public and health and medical researchers, from a range of disciplines, who have involved patients and members of the public in their research. It is designed to give the reader an overview of the key issues pertinent to patient and public involvement.

The research was conducted by Louise Locock and Anne-Marie Boylan, and was funded by the Oxford NIHR Biomedical Research Centre. To date, it has resulted in two open-access academic publications that might be of interest to readers.

- Locock L, Boylan AM, Snow R & Stanisewska S. (2016). The power of symbolic capital in patient and public involvement in health research. *Health Expectations*. DOI: 10.1111/hex.12519.
- Crocker JC, Boylan AM, Bostock J & Locock L. (2016). Is it worth it? Patient and public views on the impact of their involvement in health research and its assessment: a UK-based qualitative interview study. *Health Expectations*. DOI: 10.1111/hex.12479.

The research is also published in full on the award-winning patient experience website, [healthtalk.org](http://www.healthtalk.org).

Patient and Public experiences of involvement:

<http://www.healthtalk.org/peoples-experiences/medical-research/patient-and-public-involvement-research/topics>

Researchers' experiences of involvement:

<http://www.healthtalk.org/peoples-experiences/medical-research/researchers-experiences-patient-public-involvement/topics>

A note about language

In our research we asked patients and members of the public how they would like to be referred to by researchers. They came up with a diverse range of terms like 'patient representative', 'lay advisor', 'PPI partner', 'PPI contributor.' Given this variation, they felt it was important that researchers ask them how they would like to be referred to during their involvement. Throughout this guide they will be referred to as PPI contributors.

Background to the research

The content of this guide is based on two qualitative research studies about experiences of patient and public involvement (PPI) from the perspectives of patients and members of the public who have been involved in health and/or medical research, and health and/or medical researchers.

Ethical approval was granted by the Berkshire Research Ethics Committee (ref. 12/SC/0495).

Using a maximum variation approach¹, thirty-eight patients and members of the public and 35 researchers took part in semi-structured narrative interviews. Variation was sought across demographic characteristics (including age, gender, ethnicity, socio-economic status), and different types of involvement practice, length of involvement, type of research, and stage of career.

The interviews took place at a time and location of the participant's choice, and were video or audio-recorded according to each participant's preference. The interview opened with an unstructured section in which people were invited to discuss how they became involved or how they came to involve patients or members of the public in research. Semi-structured prompting was then used to explore other specific areas, including their motives, what they saw as the purpose of involvement, the costs and benefits of PPI and a range of issues such as payment, diversity, representation and impact. These prompts were developed based on the growing evidence base around PPI and with the input of a specialist advisory panel, which included patients, carers, members of the public, clinical and social science researchers.

The interviews were transcribed verbatim and reviewed by participants. They were coded and thematically analysed². Lay summaries are published on healthtalk.org, illustrated by video, audio and written extracts from the interviews.

¹ Patton MQ. *Qualitative Evaluation and Research Methods*. Newbury Park, CA: Sage 1990.

² Braun V, Clarke V. Using thematic analysis in psychology. *Qualitative Research in Psychology*. 2006; 3: 77-101.

Definitions, purposes and values of Patient and Public Involvement

Public Involvement is defined by INVOLVE, the national advisory group that supports public involvement, as “research being carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them. The “public” refers to patients, potential patients, carers and people who use health and social care services as well as people from organisations that represent people who use services. Patients and the public can contribute in to research in three distinct ways:

Involvement – where people are actively involved in research projects and in research organisations.

Participation – where people take part in a research study.

Engagement – where information and knowledge about research is shared with the public.

National policy is increasingly encouraging public involvement in research and the NHS National Institute for Health Research and other funding bodies now require researchers to have already undertaken PPI or to present a plan for involvement in the proposed research or if they do not intend to involve patients or members of the public, they must explain why not.

Purposes and Values of Patient and Public Involvement

Patients and members of the public bring an “expert” insight into individual research projects because of their experiences of living with a particular condition or using health services. Involving PPI contributors in research allows “the colour and nuance and diversity” of different types of knowledge to be valued and to improve research. Involving those with “lived experience” enables researchers to access a fuller understanding of the condition being studied and may help generate research which is more meaningful research. PPI also serves to challenge research that may be driven by the interests of pharmaceutical companies or individual researchers.

Involvement is about increasing public accountability, and democratising health and medical research, which is often funded using public money.



It's to make research more efficient, more accurate and more reliable, and sometimes make the results more meaningful...It kind of guides the way for researchers into what they should be researching. Because obviously they're doing research for patients, but if they don't know what patients want, that's probably not the best way forward. **Stephen, PPI representative**

I think that's what a PPI person brings – is being the person who walks into the room who is terrified for their own or their child's health and, or concerned if not terrified if you're not in a critical condition, and who constantly comes up against the medical jargon, a system of how things work... Having experienced a terminal cancer diagnosis for my husband, nothing can prepare you for the shock that you go into when you have a terminal diagnosis. And no matter how much training and no matter how many years you sat as a medical person, handing out that diagnosis and watching people in front of you, you don't know what it's like until you've been that person at home, trying to eat a dinner and throwing up at the thought of the person opposite you dying – **Catherine, PPI representative**



What can PPI add to different stages of research?³

PPI can make a number of valuable contributions to every stage of the research cycle⁴. Involvement can guide conceptual aspects of research such as defining and refining research scope and questions as well as its practical elements such as participant recruitment, writing grant proposals and undertaking the research.

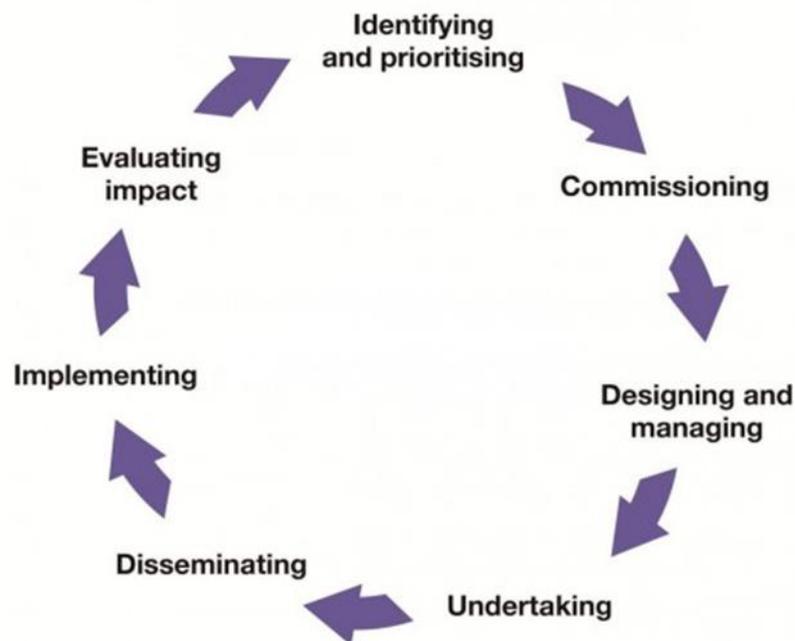


Figure taken from INVOLVE (2012) Briefing notes for researchers.

Identifying and Prioritising

Involving PPI contributors in the process of identification and prioritisation of research areas can be a powerful form of involvement as it ensures that the research priorities align with those of patients and service users.



I think the idea is that patients and clinicians together should decide which questions are important to be researched and I think that's absolutely crucial. I can't see how else it could be done and I have already taken part in a prioritisation setting partnership, being on the steering group, and also the workshop day which was an amazing day for vitiligo, which turned up with eleven I think or even twelve – we aimed for ten questions, top ten to be researched and as a result of that process which has been published in a journal so it's out there, researchers can see it, patients can see it, well you know, mostly researchers. There are two or three initiatives going on. One's already resulted in a pilot study using hand-held ultra violet light. And there's an application for a full sized multi-centre trial in process. We don't know yet - though it looks hopeful - if we'll get that. So that would be huge, there's been absolutely no research to speak of in vitiligo in the UK. **Maxine, PPI contributor**

³ This section is based on the section in the INVOLVE (2012) Briefing notes for researchers

⁴ INVOLVE (2012) Briefing notes for researchers: public involvement in NHS, public health and social care research

Commissioning

PPI at this stage of the research cycle can give a broader perspective to the review process by bringing into consideration the issues that are important from a public perspective.

Some of the ways to involve the public at this stage include:

- Having members of the public on research commissioning boards or panels
- Involving PPI contributors in reviewing research proposals
- Involving them in the monitoring process of research once the project is funded.

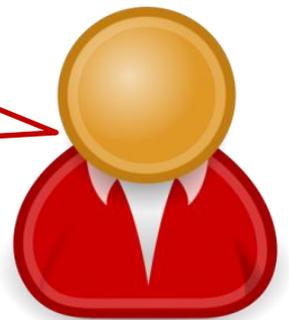


I always try and cut to the chase with a research proposal and find out well what exactly, well what exactly is the question they're trying to answer? How many people does it affect? What will happen if the question isn't answered? What will happen if it's answered successfully? What will the next stage be? Is there actually a pathway to something good happening here or is it just going to stop? So it's not something I've done a huge amount of but enough to know that it's, it's quite an important activity. And it's an activity where if you really think as a patient or as a lay person you can pose some quite challenging questions to the researchers who've come up with the idea. **Peter, PPI Contributor**

Designing and managing

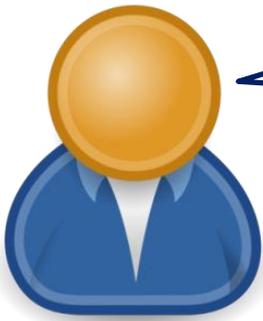
Involving PPI contributors at this early stage of the research cycle can help ensure that the research and its design are relevant to the needs of people. It can help to build and strengthen the relevance, quality and the ethics of research as well as aid the recruitment process.

I will be honest I wanted a placebo control and the families said, "No, ain't going to do it. Do a placebo control and we won't take part, people won't want to take part." And so we had a wait list control not a placebo control and I was very sorry about that but they were right in that we were able to recruit more children to the trial than we thought there were eligible children to recruit. And we hardly lost anybody and the trial worked really well and it all went fantastically. But it wasn't the trial I would have liked to have done - you have to learn to accept those compromises. **Stuart, Professor of Paediatric Epidemiology**



Undertaking

Members of the public can also contribute to conducting the research by collecting data and/or analysing data. It's important to think about the training and support PPI contributors need to do this. Their contribution can help provide another perspective on literature or in analysing and interpreting the results of research. This can help identify findings that researchers may miss or consider unimportant, and can help check the validity of the conclusions from a patient and public perspective.



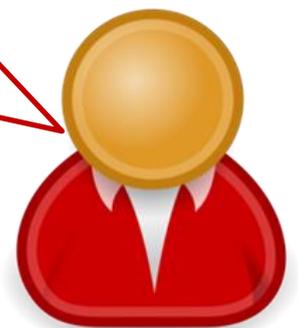
I think really you make your own involvement. So far on the project...I've sat in on patient focus groups; I've analysed patient focus groups information, which is extremely difficult. **Dave, PPI Contributor**

Disseminating

PPI contributors are more successful at the disseminating stage if they have been involved in the earlier stages of research. Through being involved from the outset, they gain ownership and knowledge of the context of the project and are able to disseminate the results through their networks.

- They can help write and summarise research findings in ways that is accessible to a public audience
- They may have access to groups or forums that researchers are not aware of
- They can co-author academic papers and disseminate findings to academic audiences – the papers we have published from this research include PPI contributor co-authors

And I sat next to Iain Chalmers in a bus going to a wine region for a reception or something and I said, "You know, I'd really like to do a review." "Yes of course you can," he said. "I'm not a scientist or a doctor." He said, "Doesn't matter. We can provide all those people as co-authors but you have the desire to do it and nobody else has, you can be the lead author." And I looked at him as though he was mad of course [laughs] and then he said, "And when you've done it you'll be an expert in vitiligo." Which I laughed out loud actually [laughs]. But in one sense he wasn't wrong because I'm not a scientist, I'm not a doctor but I know a lot about vitiligo, it's what I do [laughs] and I think the other thing that I do, which came also from my experience as an academic librarian in the science, bio sciences, is what they used to call selective dissemination of information – **Maxine, PPI contributor**



Implementing

Patient and public involvement can support and strengthen the way research is taken up in practice. PPI contributors are often passionate about ensuring that research leads to action and are able to establish relationships with key agencies and policy makers.



Then following that project there was a local project in [place name] which got set up which was looking at implementing some of the findings, it wasn't just from our project, it was , it was based with the local mental health trust and so I was working with some staff in a committee which I chaired which was, you know, sort of relatively surprising to me, and you know trying to...in fact what we ended up developing was an information booklet for the acute wards. Originally we were doing it for just [place name] but then because of changes in the Trust it turned out to be for the whole Trust. So, you know, that was, you know, I was involved in that end of the project of sort of writing up findings and then implementation work that happened afterwards. **Rosie, PPI Contributor**

Evaluating Impact

INVOLVE recommends closely documenting involvement and considering how impact of public involvement is going to be monitored and evaluated, but there are debates over how to do this and how important it is. Some PPI contributors expressed the need for receiving feedback from researchers for the work they have done so that they can see whether their contribution made a difference. See section on “Assessing Impact” (page 19) for further details.

Why do members of the public get involved in research?

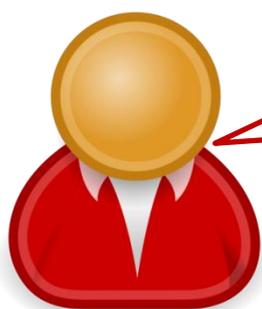
Members of the public get involved in research for a variety of personal and social reasons. For some, these are linked to personal experiences of health or social care services and a desire to bring about change in the quality of care or to improve treatments either for themselves or for others with a similar condition.

Personal Motivations

- Having something interesting to do
- Making sense of an illness experience
- Feeling passionate about an issue
- Gaining access to information
- Gaining experience and confidence after a period out of work due to illness or caring for someone
- Payment

Social Motivations

- “Giving something back” after having received publically funded healthcare
- Sense of obligation to be a “good citizen”
- Want to make good use of their existing knowledge and expertise
- Be a voice for those who are voiceless
- Religious imperatives – voluntary activities



For the PPI participant, or the PPI partner, I think it can be burdensome for them and I think there is often a lack of support for what they're expected to do. They're kind of flung in and asked to do things without a lot of help really - both in the technical aspects and also in just, you know, being asked to suddenly go into a room and collaborate with a bunch of professors, and PIs, and statisticians that they've never met before. You know, I think, I think that can be a struggle for them and potentially off-putting. **Sarah, Academic Research Fellow**

Researchers are sometimes concerned about the practical burden of research on members of the public and whether good use was being made of their time and enthusiasm. But Andrew, one of the PPI contributors we spoke to believed that there was a “huge well of enthusiastic altruism” and that researchers should not worry about asking people to get involved.

Involving People in Research

Deciding who to involve

When deciding who to involve, it is useful to think about what skills and experience PPI contributors should have. These will depend on the research question and its objectives, which may or may not require the lived experience of a condition. Certain projects may benefit from the skills of an experienced PPI contributor while others may require a novice. It can be useful to think about whether the project requires contributors with past experience of involvement in other research projects or health or social care organisations.

Brief person specifications when seeking PPI contributors may help in deciding who to involve. However, researchers sometimes worry that a more formal recruitment and selection process can undermine the notion that anyone can be involved, and reinforce researcher control over who is “allowed to be involved”.

We clearly involve people who are across the whole spectrum of experiences. Now in many ways that's almost convenience because it's who says yes. With some areas we do have to be very specific because we want people who have had specific experiences. With other areas where we're covering a huge range of potential pregnancy complications, you just want somebody who is sensible and has an opinion about what if this were to land on your doorstep. – **Marian, Researcher**

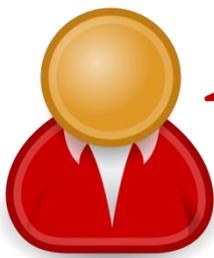


Finding people to be involved

People commonly became involved in research through having a particular condition or by caring for an ill relative. Some found out about involvement opportunities from staff providing the care. Others had taken part in medical research and found it inspired them to become more involved.

Health or medical researchers who continued their clinical practice said their interactions with patients in clinic was a form of involvement and they had ready access to a pool of people to involve, which non-clinical researchers do not. However it is important to note that time in the clinic is limited, and therefore clinical researchers cannot rely on this as their only source of involvement. Equally, people may raise different issues outside of the clinic in a more formal involvement setting.

Recruiting in a variety of ways can help ensure a wide range of people become involved, including those groups which researchers find “harder to reach” (e.g. those in full-time employment, people from Black, Asian and Minority Ethnic groups), therefore enabling a wider variety of views and experiences to be expressed.

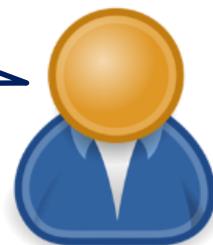


We need to think of methods...to reach out to a much wider constituency who still has a huge stake in the evidence that we create and produce, and the way that we implement their evidence in practice. Social media, digital technologies have opened up a really great potential for us to tap into people's voices. **Sabi, Senior Research Fellow**

Common ways of recruiting PPI contributors

- Through the NHS (clinics, GP surgeries, etc.)
- Using personal connections
- Inviting existing patients or research participants
- Asking existing PPI contributors find others
- Contacting support groups, community groups and charities
- Advertising in local newspapers or on the radio
- Advertising on social media sites such as Facebook and Twitter
- Schools and youth clubs

I was just talking to someone with cystic fibrosis and ...infection's an issue. "I want to get involved but actually I don't want to go to meetings through two sweaty trains and goodness knows what else if I have got a compromised immune system I'm not going to do it." But actually there's other ways they can do it – Skyping or Facebook groups or whatever. You know there's probably a thousand and one other ways of doing it. – **Suzanne, Project Manager**



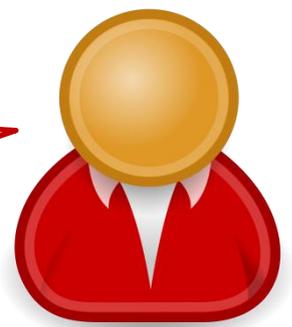
Training

Training for PPI Contributors

The training needs of patients and members of the public are subject to much discussion. There are concerns that training can tarnish the outside perspective that patients and members of the public bring. On the other hand it may be unfair to expect people to contribute without giving them a basic understanding about the research environment, terminology, and methodology.

Training can help address the “power imbalance” between researchers and PPI contributors and help them to communicate their perspectives more effectively. The type of training required will depend on the type and level of involvement.

The biggest difficulty, I think, for the lay person is to go into a very rarefied, very academic environment and learn the language. To try and coax the social and health care professional to speak in good plain English. Jargon is terrible but at the same time, you do, because it's a complex subject you do need a shorthand, so it's almost like learning another language in some instances. I've got a favourite expression is that looking at some of the documentation within research is like trying to read a Polish opticians eye chart. **Roger, PPI contributor**



The box below explains some ways in which researchers can help make involvement easier for PPI contributors

Training needs identified by PPI contributors

- Research terminology
- Medical terminology
- Acronyms
- Abbreviations
- Research methods
- Research ethics
- Good Clinical Practice
- Research process
- Reviewing documents
- Contributing effectively in meetings
- Knowing when to share stories and personal views
- Managing emotions
- Taking a wider view beyond their own experience

Training for Researchers

Whilst researchers may feel that involving PPI contributors in research is “common sense” and is just another type of professional interaction, they also said they would welcome some formal training. PPI contributors also thought it would be useful for researchers to be trained as it is their responsibility to be skilled and to provide them with the optimal involvement experience.

A mixture of views on what formal training should involve were expressed, but the researchers identified several issues on which they would like to be trained:

- Practical matters: recruitment, payment, setting up meetings
- Good chairing
- Communication
- Managing emotions and difficult conversations

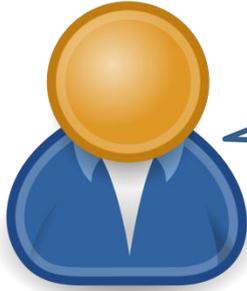
Training in mixed groups of patients and researchers may be a useful strategy which can help foster a relationship of mutual understanding as Jim explains below.



Building Research Partnerships workshops – they're nice. What's really good about them, what makes them work at that level and probably at that level only, is that it's a shared learning process and they work at their best when there's a mixed audience of professionals and lay people, because they learn with each other and they learn. The key thing about public involvement is conversation, is talking to each other and they find that in learning about public involvement they're actually, they find out half way through the day, the sort of light bulbs go on. They realise, “oh yes I've been doing some involvement.” **Jim, PPI Lead at the Health Research Authority**

Paying people for involvement

Involvement generally requires a great deal of PPI contributors' time, energy and emotion. Being involved can be costly for people who have illnesses or long-term conditions. Catherine has ME (Myalgic Encephalomyelitis) and explained that her condition makes involvement more difficult.



I've had ME for sixteen years and my health goes up and down...So I tend to find that my condition doesn't help on things like taking the time to go for training because that would then tire me for the rest of the week. If I had to drive to Manchester for a training day I might have to go the day before, I can't often just travel on the day. Most people might jump on a train at six thirty in the morning to do a meeting, I need to budget extra time into any physical transaction I have. So if I choose to attend the meeting in London at ten o'clock till four o'clock, I might make sure I wasn't doing something the next day – **Catherine, PPI Contributor**

It is important that researchers think carefully about how to facilitate PPI to ensure that they can involve the people they need to, especially when those with illnesses, caring responsibilities or jobs that complicate when or how they can be involved. One of the ways of doing this is to offer payment and reimbursement for costs incurred, including travel, accommodation, respite or childcare.

Payment for involvement is seen as a somewhat contentious issue. There are a number of different and opposing views expressed by researchers and by PPI contributors.

The concerns about payment include:

- Difficultly determining what the “right” level of payment is (INVOLVE have guidance on this)
- Payment could compromise the altruistic principle of volunteering
- Some people felt that through their contribution to research they were repaying a debt to the NHS for the care they received and therefore did not wish to accept payment
- Payment could potentially undermine the value of what people contribute
- Input may be biased if people are paid to contribute
- Payment can cause difficulties for those receiving benefits

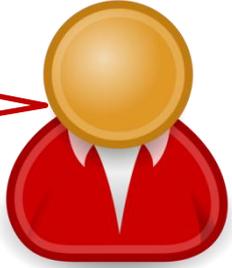
No, it's a double edged sword. I think I can see the reasoning behind it. I mean why should somebody give up their time and come and do it for nothing? By the same token I feel the same way about medicine though. Once you start and introduce fiscal rewards and things it sort of queers the pitch a little bit, and you do wonder whether you're getting, you know the best representation that you could – **David, Co-Director of a surgical trials unit**



But actually paying people presents a problem because, then some people might see it as a particular job and then you get three or four of these. I think it's an altruistic contribution to research in the same way as people participate in clinical trials, they do that without paying, and I think that is actually the ethos of patient participation. – **Carl, Professor of Evidence Based Medicine**

But payment for involvement is considered necessary for a number of reasons as it:

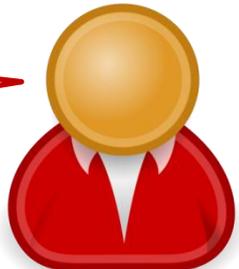
- Creates more equal relationships with professionals
- Demonstrates equal recognition of skills
- Shows that people's contributions are valued and respected
- Replaces income if people need to take time off work
- May help recruit a more diverse group of people (not only those who can afford to take time off work)



I think there should be a financial incentive which overcomes the inertia. I think a financial incentive gives you a more representative group because people who are willing to give up their own time for free are less likely to be representative than people who say, 'Well actually this is inconvenient - at least they're compensating me for the inconvenience'. Now I'm not suggesting you pay wild sums of money... But I think that if you can take away the disadvantage of participating – the consumption of time and the effort of actually turning up – if you can compensate for that financially then I think you'd get a better representation. **John, Professor of Clinical Cardiology**



I always say if the patient is the only person round the room who's not being paid, and they're doing the same amount of work as the rest of you, there's a problem. And I've talked to people who kind of go, "Oh yeah we couldn't possibly afford to pay all the patients and they should be doing it for altruistic reasons." Are you doing it for altruistic reasons? If the research is worth doing, you should be doing it for altruistic reasons shouldn't you? Do you really think that we eat nothing? We don't have any... Where do you think our money is coming from? And if you think that we all want to be doing it for free and we should be doing it for free, you're presumably, your ideal patient is not only a naïve patient but also has got a Trust fund. So that's only one kind of patient. So if you're then going back to representation then how are you going to get those ones who actually aren't? – **Helena, PPI Contributor**



"I don't think people are going to put themselves forward for that just for that money. I don't see that happening personally... In my experience people who've come into PPI they've had a genuine interest, they've been passionate about some aspect either about an illness or about a research study and whether it's worked out well in other ways, it's felt to me very genuine why they've come" – **Sarah, Academic Research Fellow**

- If children or young people are involved in paid activity, there are legal restrictions on the times and amount of hours they can undertake activities.



So, but you know, I can think of young people that kind of, have really valued having things on their CV, have asked for references, have gone on to do placements elsewhere in the organisation, thinking about their future career. But ultimately what young people, our young people said to us, and echoed something that comes through in the literature, is that they want to do it because they feel they have a responsibility and a right and a duty and they just want to. And to feel like they were paid an hourly rate to do that would maybe demean the reasons why they got involved. – **Gail, Consultant Clinical Psychologist**

Other incentives that can be offered to contributors are good refreshments, volunteering credits or certificates for people's CVs, learning opportunities and skill development, and social events.

The INVOLVE website has guidance about payment⁵, including an involvement calculator⁶ to help researchers cost PPI when applying for funding, and information about how to pay people who are in receipt of benefits, which is not always straightforward.

⁵ <http://www.invo.org.uk/posttypepublication/payment-for-involvement/>

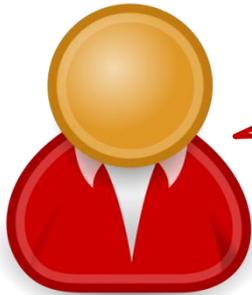
⁶ <http://www.invo.org.uk/resource-centre/payment-and-recognition-for-public-involvement/involvement-cost-calculator/>

Practical Advice for Involvement

Involvement in practice

Flexibility regarding the practicalities of involvement is a key aspect of improving the involvement experience. It can help improve the quality of involvement by enabling a greater variety of people to be involved (people with health and illness conditions or those limited by time and financial constraints). Flexibility can be incorporated into many different aspects of involvement:

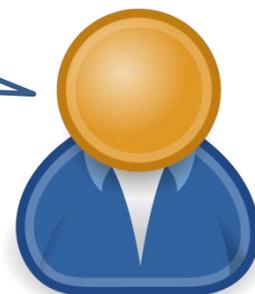
- Moving beyond traditional committee structures can be useful for a number of reasons. Universities can be intimidating environments and difficult to access for some people; a meeting in a community setting or a home visit might be a suitable alternative.
- Involvement using technology – Skype, teleconferencing or social media sites – recognises that different forms of communication may suit people differently.



I was on the phone to a meeting in Liverpool for a steering group, and somebody sat next to the telephone and ate a bag of crisps and I couldn't hear a thing that was going on [laughs], there was terrible loud crackles. And there's a limit to how much your dignity will allow you to sit at home saying, "Is somebody eating crisps there?" ...Let alone say which page of the papers that you're on. Or rustle the papers very loudly near the telephone so you couldn't hear it even if they did tell you. – **Hazel, PPI Contributor**

- Recognising that certain forms of involvement may be emotionally taxing for contributors (and researchers). In such instances it can be helpful to delegate tasks accordingly. For example, giving those who want to be involved less emotionally burdensome tasks, such as reviewing grant applications.
- Some people prefer reviewing documents in hard copy rather than digitally

Right, well in the early stages of stroke recovery, because you're aware that your speech is not as clear as it used to be, you become very self-aware and a bit tongue-tied. So face-to-face round a table is much more difficult than on a telephone, which itself is more difficult than emailing. So, I tried to structure, in the early days, as much writing as possible, so I had the document in front of me and I could take my time and organise it – **Neil, PPI Contributor**



Clarity

It is important that researchers are clear about what they expect from PPI contributors as well as the opportunities available to them. They should also avoid jargon and acronyms, and ensure they carefully and clearly explain all aspects of the research to the contributors.

Feedback

While PPI contributors recognise that research can take a long time to produce results, many said it is useful to have feedback on their contributions and updates on the progress of the research. Researchers could also ask them for feedback on their experience of involvement as a way of developing their PPI practice.

Record-keeping

Keeping a record of what PPI contributors have done and the difference they have made is useful. It can keep them motivated, help them learn what has been helpful and is useful as a record of impact. It is also worth asking PPI contributors what difference they think they made, as they might note things researchers did not realise were important.

Training

Offering PPI contributors training opportunities can greatly enhance their experience of involvement as well as its quality.

Good Chairing

Several people emphasised the importance of a good chair (whether a PPI contributor or a professional) in making meetings feel safe, welcoming, explaining jargon, encouraging everyone to have a say, and creating an atmosphere of patience and acceptance. Chairs can speak to people before the meeting or offer them a chance to ask questions privately afterwards, and maintain informal contact between meetings. There are training courses available for those who want to chair well.

Payment of Expenses

Booking and paying for travel accommodation in advance as well as reimbursing costs is a great help for those who get involved in research. (See page 13 for more on payment)

Catering

Good catering can create a welcoming and hospitable environment to foster new relationships. In arranging the catering it is important to keep in mind dietary preferences and requirements.

Creating a good atmosphere and long-lasting relationships

Creating an open and welcoming atmosphere on the day can be essential to the formation good relationships between PPI contributors and researchers. Working to build long-term relationships might extend to organising social events. Many of those involved in research spoke about how much they enjoyed contact with researchers and feeling they were treated as equal partners.

Some PPI contributors suggested that contact with others involved in research can be useful for providing peer support and learning from the experiences of others.

Other Practicalities

Having people on site may entail issues regarding safeguarding (with children and young people)

While contracts can be useful for clearly setting out roles and expectations, they can be seen as being very formal and bureaucratic and therefore may be a barrier to successful involvement

Assessing the Impact of PPI

'No matter how complicated the research, or how brilliant the researcher, patients and the public always offer unique, invaluable insights. Their advice when designing, implementing and evaluating research invariably makes studies more effective, more credible and often more cost efficient as well.' **Professor Dame Sally Davies, Chief Medical Officer**⁷

The Chief Medical Officer has advocated for PPI in health and medical research, and believes it improves research. In fact, in all funding applications to the NIHR, researchers must explain how patients and members of the public have been involved in designing the research and how they will be involved throughout the study.

Problems with assessing the impact of PPI

- Lack of agreement about what is meant by “involvement” and “impact” makes it difficult to devise suitable measures.
- Uncertainty over whether it is better to measure the process of involvement (e.g. the number and diversity of people involved) rather than trying to show a difference to the outcome or progress of the research itself.
- PPI is a long-term and complex process; it is difficult to assess impact through what might be many years of an evolving research idea.
- It is not always reported while it is ongoing; if it is not reported it cannot be assessed.
- Involvement may contribute to a change in culture that assists and enables other changes which are never directly attributed (or attributable) to that initial involvement.

The evidence base for PPI is growing⁸ and there are tools to chart and assess the impact of PPI in research. Frameworks like the Public Involvement Impact Assessment Framework (PiiAF)⁹ and Guidance for Reporting the Involvement of Patients and the Public (GRIPP)¹⁰ have been developed. It is important that PPI contributors are involved in the assessment process.¹¹ More research on the impact of PPI is needed.



I think most of the stuff about impact that I see is kind of case studies talking about, "Oh we did this," and personally I think they're often very kind of rose-tinted case studies and they're kind of like, "Well it was great because we did PPI, isn't that nice of us?" kind of thing. And I think, I think we do need to, you know, assess its impact, assess what happened with PPI, how did it impact the research if it did?

Sarah, Academic Research Fellow

⁷ Davies S. Foreward in Staley K (2009). *Exploring Impact: public involvement in NHS, public health and social care research*. INVOLVE, Eastleigh.

⁸ www.invo.org.uk/resource-centre/libraries/evidence-library/

⁹ Popay J, Collins M, PiiAF Study Group. (2014). *The Public Involvement Impact Assessment Framework Guidance*. Liverpool and Exeter: Universities of Lancaster.

¹⁰ Staniszewska S, Brett J, Mockford C, Barber R. (2011). The GRIPP checklist: strengthening the quality of patient and public involvement in reporting research. *International Journal of Technology Assessment in Health Care*, 27, 391-399.

¹¹ Crocker JC, Boylan AM, Bostock J & Locock L. (2016). Is it worth it? Patient and public views on the impact of their involvement in health research and its assessment: a UK-based qualitative interview study. *Health Expectations*. DOI: 10.1111/hex.12479



I think there is a logical 'should' in that if researchers want public funding then they need to actually make a case for what they are doing with the public. And involving people is a good way of actually uncovering the value that research gives and that there is that 'should'. But... this is a big investment that we are making, and so we ought to be contributing something. It's not just about having quite a nice time. – **Kath, PPI contributor**

There is some debate over whether it is necessary to assess the impact of PPI. Some of the researchers, like Carl below, felt that having a positive and enriching experience of involvement first-hand is an effective route to help reveal its value.

As an evidence-based medicine person you know, they expect me to say, "Where's the clinical trial evidence?" But that's not everything... You just can't run a world like that. Some things are pragmatic, make sense and actually are a good idea. Now, if we're going to spend hundreds and millions on it then maybe you do need evidence, but the idea that, actually in designing questions, designing research, I might speak to people about what it means to them as opposed to not is a clinical, pragmatic, sensible thing to do and, my experience is it'll improve your research. **Carl, Professor of Evidence-based Medicine**



Although it has intrinsic value, understanding the impact of PPI is important for justifying it to colleagues and funders, as well as improving how it is understood. More consideration around how impact can be captured is needed. Some of the researchers and PPI contributors we interviewed suggested that a retrospective analysis of funding and ethics applications or published studies could be a useful means of measuring impact. This would enable a comparison between levels of PPI and various outcomes (e.g. funding success, speed of approval, recruitment rates). However, this relies on a clear agreement of what "PPI" means and good reporting of PPI activity. Not everyone agreed that quantitative methods were the most useful for capturing impact; adopting a qualitative approach might be most useful.

Concerns about Patient and Public Involvement

Representativeness

The extent to which PPI contributors can be said to “represent” others is a common debate when it comes to PPI. Some of the concerns raised, by researchers and PPI contributors, were about the problematic nature of making changes to research based on the views of only a minority of atypical people – people that volunteer for involvement may be more interested and engaged in their own health than a typical research participant may be, for example.

However, involvement is not about having a representative sample, but about bringing a different perspective and accessing the lived experience. It is about gaining an understanding of what it is like to live with a condition every day and improving research by making it more accessible and relevant to the sample population. We never question how representative the statistician or the clinician or the researchers are, so why should we question the representativeness of patients or members of the public?



So the practicalities of putting that into practice are pretty challenging, but it will vary very much according to what it is that you’re trying to do. So if you’re the James Lind Alliance and wanting to involve stakeholders in a priority setting process then you would probably think about representatives from different interested parties. But if you’ve got a very fast deadline and you want some members of the public to take a look at your lay summary to see if it’s okay then you’re probably not going to go to the extent of worrying about if people are representative. So it kind of varies according to context – **Pam, Research Fellow**

Diversity

It is widely recognised that there needs to be greater diversity in involvement. The profile of those that usually get involved tends to be white, middle-class, retired people, some of whom have a health or research background. Having the time to get involved, but also a certain level of education and confidence to engage with research, may make involvement easier for these people.

Groups which are less likely to become involved (young and working age people, ethnic minorities, disabled people, single parents, those without a university level education, people from lower socio-economic backgrounds) may be limited by a number of practical barriers. Difficulties with access, finances and shortages of time can be addressed by being flexible in approaches to involvement (see Practical advice for involvement on page 16). Issues of power¹² and discrimination towards marginalised or excluded groups are also an important consideration. It is insufficient to expect a more diverse range of people to respond to adverts about involvement – researchers must make efforts to find them. This might entail going into their communities, targeting employers, contacting schools and university students.

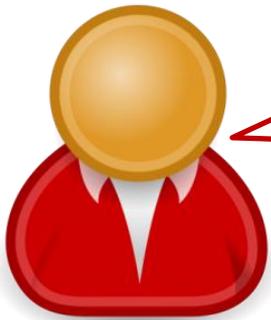
¹² Locock L, Boylan AM, Snow R & Stanisewska S. (2016). The power of symbolic capital in patient and public involvement in health research. *Health Expectations*. DOI: 10.1111/hex.12519.

Long-term involvement and “professionalisation”

A contentious issue which is subject to much debate is whether long-term involvement and training causes PPI contributors to lose their fresh “outsider” perspective and become “too professionalised”. The concern is that those involved become too familiar with aspects of the research environment – jargon, how things are done – that they lose their distance and ability to challenge researchers.

However, there are a number of objections to this perspective:

- Limiting people’s involvement on the grounds that they have developed expertise is wasteful. Some may want to move into different involvement roles and find a different project to contribute to;
- Developing expertise through training does not necessarily mean that people lose sense of the experiences as a patient or carer;
- It is important to build trust, continuity and relationships and give people time to grown into the role;
- Experience and long-term involvement may (inevitably) make contributors more effective and efficient.



And there's been a lot of going round and round in circles about people who get involved and stay involved for a long time become professionalised and what does that mean and does make them less lay. And, well if you involve somebody who's got no experience how are they going to add value because they don't know what they're doing, but then everybody had to start somewhere. So, these arguments are slightly self-defeating, a little bit frustrating and I think you need both. You know there are lots of people who've been involved for a very long time. I know quite a few people who, you know whose; you know lived experience was ten, maybe twenty years ago, but for whom it's fresh. You never forget a significant experience either as a patient or a carer; it never goes away. Your perspective on it, and the way you channel what you've learnt from that experience may change, but you don't lose that perspective; you just gain more experience. So, you have more experienced and less experienced people, not professionalised people really and I think it's important to have both. **Jim, Public Involvement at the Health Research Authority**

With greater experience the roles that PPI contributors undertake can change. Instead of excluding people with more research experience it may be more helpful to consider the purpose of the particular type of involvement and the kind of perspective required from contributors and assign tasks accordingly.

I do think people are still useful. I firmly believe that. But that happens in all walks of life. You don't say someone has suddenly ended their shelf life as a something just because they reach a certain age or at least we shouldn't. It's whether or not they can still make a contribution and the beauty of PPI is that there are always opportunities to make a contribution somewhere else. **Richard, PPI Contributor**



Feelings about Involvement and Emotional Impact

Patient and public involvement can be an emotional experience for researchers as well as those who become involved.

Positive Experiences

PPI can be enjoyable and rewarding. Researchers described feeling energised, inspired and enthused, and feeling that it made their research more worthwhile, relevant and interesting.



So I think there's a big impact for us, it makes it all very real and meaningful and, like I say, fun. The most amazing impact is seeing how; hearing some of our parents talk about their experience of being involved with us. And that's very moving really because they've often been quite disempowered through becoming parents of disabled children and they had significant struggles and hearing them talk in presentations or even on TV recently, you know, about how being involved in research has really helped give them their self-confidence and being, you know, feeling like they make a difference to – for the benefit of other families and, you know, it's amazing. **Chris, Health Services Researcher**

Challenging Experiences

Involvement can also bring a number of challenges. Some researchers expressed frustration and unhappiness about the discourse surrounding PPI that casts them as unfeeling and inhuman. Researchers can feel anxious about doing PPI well. They can find it “stressful”, “draining”, “exhausting” and “nerve-wracking”. As one said, it can be “challenging being challenged”. It can feel threatening to have people lay, commenting on your research, and it may feel uncomfortable to deal with the tension and conflict that may arise. Researchers often feel personally responsible for the emotions and expectations of the people getting involved, which can be distressing.

And, you know, 'I've been, I've been working on this for nine years now and I don't want to be told that I don't understand things.' And, you know. And that I think is sometimes dangerous, I think sometimes as a kind of an implicit and sometimes actually explicit kind of storyline in this idea that we need PPI because actually we're all these kind of you know, robotic, unfeeling people who don't understand what patients go through. **Sarah, Academic Research Fellow**



Why don't we just [effing] bring a load of patients to come and sit round my desk? Why did I bother doing a PhD? Do you know what I mean? So it's like really difficult because these people are quite capable people, but they've not had the training, they've not worked as a researcher. You know everyone knows that to be a researcher you've got to cut your teeth, you've got to do at least three degrees: you've got to do an under-graduate, masters and PhD. You've got to, you know, you cut your teeth in your first research assistantship where you're closely monitored and evaluated. And then at the opposite end of the spectrum they just want to bring in these people who've got nothing to do with anything and let them loose on our study – ill patients at the bedside. It's really difficult for me so I've got to kind of be really careful how I manage it. – **Ann, Health Services Researcher**



Feeling Ambivalent about Involvement

- Some researchers feel under pressure to do PPI because it is “trendy” and “politically correct”
- Researchers can also feel disempowered and vulnerable, unable to criticise involvement

Mm about sixty percent I want to do it. The bits of me that don't want to do it are the kind of, 'Oh god I've got to be polite to people when I'm not in the mood to be' [laughs] – all that kind of stuff. And this sense of oh I've got to, there's a word for it. When you're sort of smiling and endorsing one way of doing something and inside you're thinking, 'I know this is a waste of time,' or pretending something is true which isn't, I feel really isn't true and that's, I'm giving you very mixed up response here aren't I? But that, no on balance I think, 'Well kind of, it's a nice thing to do and it might make a bit of a difference but I don't think it makes that much difference.' But the public message we have to sort of endorse and support is, 'it's terribly valuable and important and makes a massive difference.' So I think that to sort of disjunction between what I think inside and the kind of the public story, I feel uncomfortable with. So that's one reason for, yeah, the reason for my forty percent – ooh don't make me do it. **Alison, Senior Research Officer**



Colleagues' attitudes to PPI

Colleagues' attitudes towards involvement, both locally and more broadly within their profession or within research, can affect researchers' confidence and enthusiasm. Supportive and enthusiastic colleagues, particularly principal investigators, can create a helpful environment for researchers involving patients and members of the public.

However, in some cases colleagues may appear hostile, sceptical and dismissive about involvement, or uninformed. Reasons for these attitudes may include:

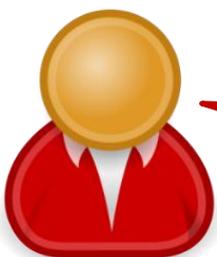
- wanting to stay in control and maintain power
- concern that PPI may threaten the scientific rigour of their research
- worry that PPI only offers a few “unrepresentative perspectives”
- feeling that PPI contributors would just make irrelevant remarks
- the significant amount of time and effort that involvement can take

Involving Senior Colleagues

Support from senior colleagues is considered particularly helpful and important. There is a concern that involvement is often left to more junior researchers on short-term contracts, resulting in a loss of momentum and continuity when the contract and the study end.

However, involving senior colleagues can be challenging and researchers can find themselves facing a number of objections.

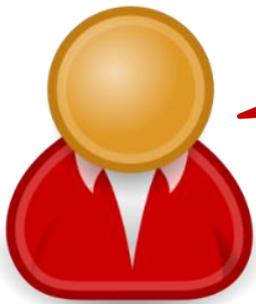
I suppose the only other thing is that I think don't under estimate how tricky it can be when a more senior person has more negative, not negative necessarily, but has more set views on what PPI can and can't do. **Alice, Research Associate**



Quite honestly, the very senior people think this is a waste of time and a box-ticking exercise. And a lot of what I've been doing I've been keeping it quiet, because I don't want anyone to tell me that I'm wasting my time. And I can justify it from a point of view, "Well we need to tick that box" and, you know. And I've been, I think it was at [a] conference I was at somebody from NIHR was speaking. And he said, "You all don't seem to realise that that box is really important and we will reject proposals that we're, there's nothing there, there's nothing adequate." **Bernadette, Clinical and Academic Haematologist**



Whilst some researchers may worry that PPI is a waste of time and adds unnecessarily to an already busy workload, if PPI is well supported and done to a high level, it has the potential to reduce workload and improve efficiency – for example, through aiding the recruitment process, writing lay summaries, or conducting literature reviews.



But because of that there's a very strong culture of involving people from the top down; the head of department sits with the group at their meetings. He's very, he thinks – well. I don't want to put words into his mouth, but I think that's very important to show that it is important, and it doesn't just happen, and it maybe feeds in. He's sat there. **Rebecca, Research Fellow**

Organisational support and leadership for PPI

Researchers commented that there ought to be greater awareness-raising about what organisational support is available for researchers undertaking involvement. Funders and national bodies, in particular the NIHR, are thought to have a central role in creating momentum and encouragement for PPI. Advice and support are available from NIHR INVOLVE and the local Research Design Services. While there is still a feeling that a firmer national steer is required on some issues, there has been substantial change over the years and NIHR's recent strategic review "Going the Extra Mile" addresses some of these concerns and recognises the need for a whole-system change and approach.



You go to the system level because that's what drives organisations, in part of course they're driven by the individuals and how they want to be but they're also driven by what the system is. So the NIHR has been fantastic, I mean the NIHR has been one of the great advances in research for me in this country absolutely fabulous great people involved and they've done a fabulous job and they have become powerful and committed advocates for this approach. **Stuart, Professor of Paediatric Epidemiology**

Structural, organisational and cultural factors which can aide involvement include:

- A supportive culture, strong senior leadership and role models, and principal investigator commitment
- Specialist PPI coordinators who can: offer practical support and guidance; moral support and encouragement; build long-term relationships with patients and members of the public; provide expert facilitation
- Local administration teams can be helpful in organising meetings and maintaining contact with people involved.
- Funding for involvement beyond specific grants
- Moving beyond a short-term focus on each study and instead refocusing on investment in core infrastructure (e.g. dedicated staff time, guidance and training)

The way we make it work, to the extent that we do, is by having someone who champions it here. And then, and it's a real ethos throughout the whole team. And our admin staff actually play a really strong role in maintaining contact with our service users as well. And so it's a very personalised thing. So I do think that's worth the money because, I do think that we have confidence that we're always including service users in all our projects at every stage. However, I still don't think we're getting that quality. **Ann, Professor of Health Services Research**



In addition to accessing the range of guidance and support available from NIHR INVOLVE, researchers also recommend attending INVOLVE's biennial conference as a way of learning from others' experiences and creating a sense of community of practice among those engaging with PPI.